



**MERRY CHRISTMAS
and HAPPY NEW YEAR
from the PenCRU team!**



Have you got an idea for a Building a Partnership shared learning event?

We hosted another very successful Building a Partnership day on November 10th. We had a number of requests from members of the Family Faculty to repeat the training we did in June titled:

Would you like to know how to find reliable information about your child's condition on the internet?

Here are some of the comments of the day: *'The event was well organised and highly informative; I really enjoyed myself, too!'*

'very well organised and informative'

'very informative, very friendly and useful.'

'a really useful opportunity to meet other parents.'

'very good organisation, was able to participate within group and all relevant information.'

We would very much like to develop Building a Partnership and would welcome any suggestions from you about topics you may like some 'shared' learning on. We have two suggestions so far: '

Decoding medical language once you have found the journal articles'

'Training on basic research methods'

If you have any suggestions we would love to hear them!



Project update

Informing the NHS Outcomes Framework: what outcomes of NHS care should be measured for children with neurodisability? (CHUMS)

In the last newsletter, we told you about a new project asking the question: what outcomes of NHS health care should we be measuring in children with neurodisability? The project is now well underway.

Co-Investigator's Meeting: In November, we held a very successful meeting with a group made up of study co-investigators (academics and clinicians involved in the management of the study) and parents from the Family Faculty. During our day together, we had detailed discussions of each of the three parts of the study: i) the systematic review of literature; ii) the qualitative study involving focus groups and interviews with parents and children affected by neurodisability; and iii) the survey that will be conducted with healthcare practitioners who work with children with neurological conditions. The meeting was very helpful in making some important decisions about how the study will be run.

Ethics approval: Before we can go ahead with the project, we have to receive approval from an ethics committee. The purpose of the ethics committee is to ensure that the research being done is of good quality and value and will not put the participants at any unnecessary risk or distress. The committee decide whether we are allowed to do the study and whether there are any aspects of the study that they think should be changed. Currently, we have sent the ethics committee all of the study paperwork and, following a committee meeting held last week, we should receive their decision in the next few days.

Systematic review of literature: We are making good progress with the literature review which will bring together the findings of studies that have already used outcomes to measure health care in children affected by neurodisability. We hope to begin reviewing the literature in the New Year. The first step in the review process will be to search the large number of electronic resources using some key words about parents, children and outcome measures, looking for previous studies carried out in this area.

Qualitative study involving focus groups and interviews with children & parents: We have made very good progress in planning this part of the study and preparing all the necessary paperwork. It was this part of the project that the ethics committee were particularly interested in, as it is their role to ensure that the children and parents involved will not be put at any unnecessary risk or distress. Subject to receiving their approval, we hope to begin recruiting participants in the Spring 2012.

Survey of healthcare professionals: We are also making good progress in planning this part of the study. The discussions that we had with our co-investigators in November proved very helpful in making decisions about the management of this part of the project. If you would like to know more about this project or be involved, please contact Becky on rebecca.taylor@pcmd.ac.uk or 01392 726002.

Improving communication with disabled children when they have to spend time in hospital

At the moment we are interviewing nurses from Bramble Ward (RD&E) and Caroline Thorpe Ward (Barnstaple) about their experiences of caring for children with communication difficulties on the ward. These will be analysed alongside interviews that have previously been carried out with parents, children and other health professionals. If you would like to know more about this project or be involved, please contact Claire on claire.lloyd@pcmd.ac.uk or 01392 722901

Peer Support Project

This is a project looking at the benefits and costs of providing peer support to parents of disabled children. Since the last newsletter, we have been working with our stakeholder group, made up of parents from the family faculty, volunteers and staff from Face2Face and representatives from the NHS, Devon County Council and various charitable organisations, to develop the plan for the project. This has now been submitted to an ethics committee who will decide whether we are allowed to do the study and whether there are any aspects of the study that they think should be changed. We hope to have a decision from the ethics committee before Christmas. If you would like to know more about this project or be involved, please contact Val on val.shilling@pcmd.ac.uk or 01372 726041



Working groups

What is a working group?

When an issue or query has been prioritised, the first stage in turning this into a research proposal is to set up a working group. This is a group of people who are particularly interested in the topic and who are willing to feedback and share their ideas, experience or expertise. This group could be made up with families, professionals and members of the research team. The group will meet several times to think about how to turn the issue into a research question using the PICO format, to think about the practicalities of a research project, and to develop a protocol. They will consider if this topic can be carried forward for research and explore potential funding.

Current working groups:

Active computer games

The next steps for this project are to carry out more detailed searching of the existing literature. We hope to be able to use this information and continue to work with families and professionals to start to narrow down and develop our ideas. We have bought the next meeting forward as we are hoping to submit a research question to be considered for PenCLAHRC funding.

Next meeting December 8th, 10.00 –12.30

Social inclusion

We are developing a research programme to promote the social inclusion of disabled children. Several meetings have been held with parents and health and social care professionals to outline potential lines of research activity.

Next meeting January 19th, 10.30-12.30

NEW working groups :

Involving Children in research

We have been discussing for some time the need to involve children in the work we do. This working group setting up about how to involve children in our work. We would like to set up the group to discuss and explore ideas about how to best go about this. If you have some ideas then please get in touch.

meeting 2012 TBC

Travelling working group

At a recent PCV in Barnstaple we discussed the possibility of hosting a working group day in north Devon to discuss the above projects, as it was raised that travel time is an issue for families. We are hosting the first one in February in Barnstaple; if you would like to come along please get in touch. We hope to be able to do the same in south Devon next year too.

North Devon meeting, February 22nd 10-2.30pm

Where we've been:

The PenCRU team had a lovely morning in Honiton on Saturday 25th November at the [Millwater School Christmas Fayre](#), we took along our PenCRU balloons and had fun blowing them up and handing them out to the children, we all did very well in the raffle too!

If your school has an event coming up next year that you would like us to attend we would love to come, balloons and all.

We also presented a workshop at the [American Academy for Cerebral Palsy and Developmental Medicine \(AACPD\)](#) in October. The workshop was titled: *'Involving families of disabled children as meaningful partners in all stages of research'*. It was very well received.



Recent publications:

Cerebra Monthly Briefings:

Cerebra asked us to write two articles for their October and November monthly briefings. The first article is a compilation of four of our 'What's the Evidence?' reports:

<http://tinyurl.com/bn3klyy> .

The second is a guide entitled 'Finding and Appraising Information and Evidence on the Internet'. <http://tinyurl.com/d958t79>

Staff update:

Sarah Bailey has just been appointed as a researcher with PenCRU, and will start working with us at the end of February next year. Sarah's role will be similar to Claire's and involve reviewing evidence and developing ideas for research projects with families. We will ask Sarah to tell you more about herself in the next newsletter.

We are sorry to announce that Becky is leaving us at the end of January. Becky has done fabulous work in getting the CHUMS project up and running efficiently. We wish you all the best for the future Becky!

We are currently advertising for a Research Fellow to carry out work on the CHUMS project and will update you in due course you in the next newsletter.

Meetings and events:

PenCRU meetings:

Computer games working group

Date: Thursday 8th December

Time: 10.00 am—12.30

Location: Veysey room 006

Social Inclusion working group

Date: January 19th, 2012

Time: 10.30-12.30

Location: Veysey room 115/112

North Devon working group day

Date: February 22nd, 2012

Time: 10-2.30pm

Location: Cedars Inn, Barnstaple

Involving Children working group

Date: TBC 2012

Time:

Location: Veysey

Reminder: We are able to pay for travel expenses and child care costs. We are also able to pay an 'acknowledgment' fee for your time.

Seminars

Brahm Norwich seminar

Date: February 2nd, 2012

Time: 12-1pm

Location: Veysey lecture theatre

Contact the team:

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